

SUMMARY OF DISCUSSION

NCBDDD External Partners Group Conference Call

Date: Friday, February 13, 2004; **Time:** 1:00-2:30pm (EST)

Participants: Clarke Ross, Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD); Jane Correia, National Birth Defects Prevention Network (NBDPN); James Rimmer, National Center on Physical Activity & Disability (NCPAD); Barbara Kilbourne, National Center on Birth Defects and Developmental Disabilities (NCBDDD); Lowell Sever, Past Chair of EPG; Jeremy Scott, Tourette's Syndrome Association (TSA); Emil Archambault, B&D Sagamore; George Jesien, Association of University Centers on Disabilities (AUCD) and Trista Sims, AUCD. Approximately 20 other people participated in the call as observers and were given the opportunity to make comments a number of times during the call.

Introductions and Overview of Agenda

The conference call began at 1:33pm. George J. briefly described the format for EPG conference calls. EPG Executive Committee will open up conference calls to the entire Partners Group. The format of these calls will consist of the Executive Committee conducting the business meeting with opportunities for input from other Partner participants at specific times during the meeting, where appropriate, and with additional time for general comment and input toward the end of the call.

Members of the Executive Committee followed by members of the larger Partners Group, briefly introduced themselves, their organizations and their professional backgrounds. George J. briefly discussed the December 19th meeting minutes and asked if there were any corrections or modifications. James R. approved the December 19th meeting minutes and Michael B. seconded.

NCBDDD Strategic Planning Process

Barbara K. reported on the NCBDDD Strategic Planning process. This process is in the preliminary stages and will be based on the "Futures Initiative" underway for all of CDC as it develops its overall strategic plan. NCBDDD has contracted with the Booz-Allen consulting firm to assist in the strategic planning process and to survey and gain feedback from the CDC staff and the EPG. This planning process will assist in determining the direction and priorities of the NCBDDD over the next ten years as well as identify the emerging needs of the Nation in relation to the mission of the NCBDDD. Also, it will focus on determining the relationship between the Healthy People agenda and how the Center's strategic planning process fits into that agenda. A survey will be distributed to the EPG and can be completed via online, mail, or by phone. Lastly, it was suggested that Booz-Allen conduct a semi-structured focus group of EPG members sometime in the near future in addition to the survey. The Executive Committee suggested that Public Health week may be an opportune time to conduct face-to-face focus groups. Barbara K. will discuss further at NCBDDD and with Booz-Allen.

Vice-Chair Reports

Clarke Ross - Vice Chair for Education and Advocacy

The Education and Advocacy Committee has established a listserv for their committee. Also, they are working on developing the overall “message”, possible activities, and publicity for the NCBDDD conference and Public Health Week.

Jane Correia - Vice Chair for Membership, Finance and Communication

The Membership, Finance and Communication Committee is working on a concept document and reemphasized that the by-laws will not be too formal, but rather provide general guidelines to provide parameters under which the EPG will function and also serve as another instrument to describe the work of EPG. The by-laws will be renamed as “operational guidelines” and will be forwarded to Barbara K. They will be completed by the end of February and will be sent to the entire EPG. Also, it was suggested that they can be distributed at the NCBDDD conference as a handout or resource.

James Rimmer - Vice Chair for Policy and Programs

The Policy and Programs Committee will be assisting with the analysis of the survey results for the NCBDDD Strategic Planning process as mentioned above.

Jeremy – External Liaison

Jeremy S. will keep the EPG website up-to-date and will not be developing 1 pagers since all of the EPG information can be accessed on the website through links to each of the Partner organizations.

Discussion of Possible Public Health Week Activities & Materials – April 5-11, 2004

Hill Lunch Briefing

Jeremy S., Serena L. and Emil A. will be taking the lead on this activity. It was suggested that the group needs to establish a date, time, and topic before planning the event. The financial costs of sponsoring this luncheon was also discussed and the possibility of boxed lunches (approximately \$15/box for 50-100 people, totaling \$1200).

The EPG wants to educate Congress about the NCBDDD especially since there is a high staff turnover rate on the Hill. It was suggested that we conduct a panel of four (i.e., Dr. Jose Cordero, NCBDDD Division Directors) to speak on the overall purpose and goals of the NCBDDD and possibly EPG members that are affiliated with the Divisions can talk about specific topics. Another suggestion was that each Division could highlight specific issues that are of current interest on the Hill (i.e., folic acid) and invite a person who has benefited from the work of NCBDDD. Other suggestions were to talk of the future of the NCBDDD and to have fewer speakers (no more than 4/5) presenting for 1-1 1/2 hours.

Jeremy S. and Emil A. will develop a 1-page proposal identifying the cost, invitees, and a date, as well as a letter of request for financial support to the Group for \$100 or more per organization. The Executive Committee will decide on where an account should be developed to manage the contributions.

Activities for 2004 NCBDDD Conference – July 26-28, 2004

EPG Meeting

The EPG meeting has been scheduled for Sunday, July 25th from 3-5pm.

Exhibits

The EPG exhibits will be placed together for networking purposes. Barbara K. will send out additional information to the Group on how to exhibit.

Hill Event

The Hill event will be held on Tuesday, July 27th and will focus on the mission and vision of the NCBDDD. Some suggested topics were to talk about the economic benefits of folic acid, early screening, and to acknowledge the 14th anniversary of the ADA

Awards

Barbara K. is working on developing the criteria for possible awards to be given by the EPG. There were many suggestions for the categories of awards such as: a Senior Distinguished Contributor Award, a Programmatic Award, a State Award, a President's Award, a Legislative Award, and an Individual Award for individuals who have contributed significantly to the Network and its activities. However, it was concluded that the Group should start off with one legislative award to begin with and as the EPG grows, additional awards can be added in the future. The legislative award could be awarded to individuals who were involved from the beginning such as the Congressional "Founding Members" of the NCBDDD (i.e., Senator Bond, Jo Ann Emerson). Criteria will have to be developed and the Godfrey P.Oakley Award can be used as a model. It was also decided that the awards should take place during the luncheon due to a larger attendance than at the Hill event. Lastly, the possibility of inviting a celebrity such as the Doles, George Will, or Judy Woodruff (who presented at the last conference), were discussed . The entire Executive Committee was asked to think of possible people and individuals who may have relationships or contacts that could help facilitate an invitation.

National Meeting Symposium

Barbara K. submitted a symposium proposal for the National meeting which would provide information on the function and activities of the EPG. She is awaiting word on whether the proposal was accepted or not. Once we hear, we will need to decide on the presenters and develop a coherent outline for the session.

Wrap Up

Opportunities to Participate

George J. asked if there were any comments from other EPG members on the call and encouraged all those on the call to contact the Vice Chairs of the various committees directly if they would like to participate in any of the activities discussed. Barbara K. will send out an email containing all contact information and will post to the Partners' Site on the NCBDDD website. Additional feedback can also be sent to Jeremy S. concerning these activities, as well, as he serves as the External Liaison for the EPG. His e-mail address is: (tsdc@tsa-usa.org) and telephone is: 202-408-6443.

Meeting adjourned at 2:30

*** The next meeting of the Executive Committee has been scheduled for Friday, March 12th @ 1:30pm.**